

# Dementia Care Action Plan Consultations

## Public Engagement Session Discussion Guide





# Introduction

Dementia is a brain disorder that affects all aspects of a person's physical and cognitive functioning. While not a normal part of aging, aging is a risk factor for developing dementia. People living with dementia need supports which change as the disease progresses. People living with dementia have goals for the future and a continued desire for meaning and enjoyment in their lives. The type of supports required need to reflect these goals and the dignity inherent in all people.

According to the Alzheimer Society of Newfoundland and Labrador, there are approximately 9,600 people in this province living with dementia. This number is projected to increase to over 14,000 by 2035. Therefore, the Province must respond to the needs of people living with dementia, their families and care partners, now and into the future.

Nationally and internationally, organizations and countries including Canada, are preparing to address the needs of people living with dementia and their families. The World Health Organization's Global Action Plan on the Public Health Response to Dementia, 2017-2025 ([who.dementia/action/plan](https://www.who.int/dementia/action-plan)) outlines proposed actions to improve the quality of life for people living with dementia, and to reduce the impact of dementia on communities and countries. Further, there is recognition from the United Nations that a human rights-based approach is required when addressing dementia. ([ohchr.org/Dementia and Human Rights](https://www.ohchr.org/Dementia%20and%20Human%20Rights))

On June 17, 2019, the Federal Government released A Dementia Strategy for Canada: Together We Aspire ([canada.ca/national dementia strategy](https://www.canada.ca/national-dementia-strategy)). The objectives of the strategy are to:

- prevent dementia;
- advance therapies and find a cure; and,
- improve the quality of life for people living with dementia and their caregivers.

In *The Way Forward*, the Government of Newfoundland and Labrador committed to implement a Dementia Care Action Plan that increases awareness, improves supports and services for people living with dementia and their care partners,<sup>1</sup> and improves the capacity of the workforce to better support individuals living with dementia and their care partners. The Department of Health and Community Services is responsible for leading the development and implementation of the Dementia Care Action Plan.

Meeting the needs of people living with dementia and their care partners will require evidence-based and individualized approaches and services. People living with dementia and their care partners interact with many parts of the health care system, including family doctors, hospitals, home support, personal care homes, long-term care homes, and palliative and end-of-life care. Throughout the dementia journey, care and support needs change. It is therefore important to help people understand what services and supports are available, and how to access them.

<sup>1</sup> Care partner is a term used throughout this document to describe those who provide concrete and emotional support, not as part of a job, but because they are related to the person by family, marriage and/or friendship.

Input from people living with dementia, their families, care partners, and health care providers, is essential to ensure the actions in this plan meet the needs of people living with dementia. Feedback from the engagement sessions will directly inform development of the plan.

The Department of Health and Community Services is seeking feedback regarding gaps and potential actions in relation to three main areas:

- awareness and education;
- supports and services for people living with dementia, their families and care partners; and,
- workforce development.

## A. Awareness and education

The causes of all types of dementia are not fully understood, however emerging evidence suggests there are potentially-modifiable risk factors including: smoking, obesity, and alcohol use. Education may support a delay in onset and/or decreased incidence of the disease.

Early detection means people may have earlier access to treatments, therapies, education, and supports. Earlier diagnosis may allow time for the person living with dementia to be an active participant in planning for their future. Awareness of early signs of dementia and knowing that supports are available may encourage people to seek a diagnosis sooner.

Health professionals have reported that some care partners isolate themselves due to worry or fear about reaction to their loved one's dementia. This can lead to decreased quality of life for both the person living with dementia and their care partner. Education about dementia and the supports needed for community inclusion will help support dementia friendly communities and reduce stigma associated with a diagnosis.

According to the Alzheimer Society of Newfoundland and Labrador, stigma is one of the most significant challenges for people living with dementia and their care partners. Stigma prevents people from talking openly about their experience and knowledge and seeking help.

1. What are the gaps in awareness and education with respect to dementia?

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2. What actions would you suggest to address the gaps?

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3. Proposed actions to include in the Dementia Care Action Plan.

- Increasing the capacity of the 811 HealthLine to provide information about dementia.
- Development of standardized information package 'toolkit' for clients upon diagnosis.
- Partner with the Federal Government on the development and delivery of public awareness campaigns.

Do you think the proposed actions will be helpful to include in the Dementia Care Action Plan? Why or why not?

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## **B. Supports and services for people living with dementia and their care partners**

From the time of diagnosis, people living with dementia and their care partners require information, services and supports to live well with dementia. As the dementia advances, needs change, and additional supports such as home support, out-of-home respite, supports for managing behavioural symptoms, and residential care may be required. People do need help to transition from one service or care setting to another.

According to a recent report entitled Dementia in Canada by the Canadian Institute for Health Information, care partners provide significant support to people living with dementia, which can be challenging and overwhelming. Timely access to respite support and help in navigating the health care system are challenges that have been identified.

The Department of Health and Community Services, in collaboration with the regional health authorities, is working to improve supports to people living with dementia.

Enhancing timely access to community-based care is being achieved through the Home First Initiative. This health care management philosophy is designed to facilitate a quick response to the provision of community-based services. These include: home support, rehabilitation, nursing, counselling, and provision of medical supplies to clients with complex care needs, and those requiring end-of-life care, to support them to remain at home and avoid emergency department visits, hospitalization and premature long-term care placement.

In addition, the Provincial Home Dementia Care Program is providing people with moderate-to-late stage dementia and their families, ready access to a family doctor and nurse practitioner at home. Beginning in Eastern Health with a goal to spread across the province, this project provides intensive case management support to clients living with moderate-to-advancing dementia, their care partners, and their primary care physicians by providing rapid access to information about care concerns.

The Province and the regional health authorities are working with the Canadian Foundation for Healthcare Improvement to address inappropriate use of some medications in long-term care homes.

1. Based on your experience, what are the gaps in the current services that exist for people with dementia and their care partners?

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2. What actions would you suggest to address these gaps?

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3. Proposed Actions for inclusion in the Dementia Care Action Plan:

- Increased access to adult day programs to provide meaningful activities for people living with dementia and respite for care partners.
- Improved care co-ordination across all health care settings through all stages of the disease.

Do you think the proposed actions will be helpful to include in the action plan? Why or why not?

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### C. Workforce development

People living with dementia need health care providers who are knowledgeable about dementia. This includes family physicians, hospital staff, home support workers, and staff in residential care homes. The national dementia strategy highlights the need for a skilled workforce, and acknowledges the direct relationship of well-trained workers to a better quality of life for people living with dementia.

A recent report, entitled *Dementia in Canada*, by the Canadian Institute for Health Information, states that primary care physicians in Canada report they are less prepared to support their patients living with dementia than physicians in other countries. In Newfoundland and Labrador, health professionals report they need access to evidence-based and up-to-date information on dementia care. Feedback from clients and families through the national dementia strategy consultations noted gaps in knowledge of some health care providers.

1. What are the gaps in education/knowledge/skills of the workforce with respect to dementia?

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2. What actions do you suggest?

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